

ADVANCING PALLIATIVE CARE IN KUWAIT:

A Global Perspective

by Maryam AlBahar, MS, CCLS

My country of Kuwait is home to approximately 4 million people from different backgrounds, races, religions and ethnicities. A small but vibrant country, it is situated in the heart of the Middle East. Its healthcare system, characterized by a combination of public and private services, plays a pivotal role in ensuring the well-being of its citizens. However, within healthcare, pediatric palliative care (PPC) services remain a slow, emerging field, presenting both unique challenges and opportunities. This article aims to delve into the landscape of PPC in Kuwait, addressing the barriers, discussing cultural perspectives, the progress of PPC and services available to patients and families, exploring the role and challenges of Child Life Services, and charting the path towards a promising future in pediatric palliative care within the country.

Barriers to Pediatric Palliative Care in Kuwait

Providing PPC in Kuwait faces significant challenges rooted in cultural, societal, and healthcare system factors. A notable issue is the limited availability of PPC-specific educational and training opportunities within Kuwait. Kuwait University's School of Medicine, for instance, lacks courses in palliative care, and there are no training programs for medical students or residents interested in this field. To pursue palliative specialization, specialists must seek education and training abroad, resulting in a shortage of qualified

PPC professionals in Kuwait, including doctors, nurses, and child life specialists. Moreover, the lack of local research and data on PPC complicates matters, with a limited number of studies



Sultan was diagnosed with Sanjad Sakati Syndrome and recently passed away in December 2023 at the age of 24. The photograph below was taken in 2019



Author Maryam AlBahar, MS, CCLS supporting a child during a procedure

conducted in Kuwait. As of 2023, there are only two studies on PPC services in Kuwait, making it challenging to develop evidence-based practices tailored to Kuwait's unique context.

Cultural Perspectives

While Kuwait boasts modernity and grants its residents considerable lifestyle freedom, it remains rooted in cultural conservatism when viewed through a Western lens. Certain cultural norms persist, such as gender-segregated schooling and the influence of patriarchal values, particularly prominent in nomadic and Bedouin communities. Traditionally, the preference for familial support over seeking assistance from outsiders has been paramount, with discussions surrounding mental health support only recently gaining traction after the COVID-19 pandemic.

Cultural perspectives in Kuwait significantly influence the acceptance of PPC. To ensure effective PPC in this region, it is crucial to

comprehend these cultural dynamics that influence healthcare decisions and preferences. For many professionals, palliative care is connected with treatment failure or thought of interchangeably with the practice of “do not resuscitate” (DNR), raising moral, spiritual, and legal concerns. Other misconceptions about PPC from caregivers, such as associating it exclusively with adult care or hospital settings, can impede access to necessary services for pediatric patients and families.

The belief that PPC only provides medical support and the reluctance to seek help from unfamiliar sources are other reasons families are reluctant to embrace PPC. A revealing incident with a concerned mother at the beginning of my career underscores the need for corrective measures. As I excitedly shared the possibility of obtaining a hospice referral for her child at the cancer hospital, I was met with a terrified whisper from a mother. “That’s where children go to die,” she worriedly shared, “even if they were doing better. All the mothers talk about it, and it’s best to stay away from that place.” In these cases, parents may delay PPC, and a child’s mental and physical health may deteriorate unnecessarily without proper palliative care. These deep-rooted misconceptions must be met with appropriate education, support and information.

Progress of Pediatric Palliative Care in Kuwait

Significant strides have been made in advancing PPC within Kuwait’s healthcare landscape. Currently, there are three specialized Pediatric Palliative Care professionals from Kuwait, including Dr. Ahmad Jaafar, Dr. Emma Alkhabaz, and Dr. Qutaibah AlOtaibi, each with a distinct international training background. Notably, Dr. Salman AlTowalla, the Head of the Pediatrics Department at Al-Adan Hospital, a local government hospital, introduced a specialized in-hospital pediatric palliative care unit called the “Complex Care Unit” in collaboration with Dr. AlOtaibi, marking a momentous achievement. Furthermore, Bayt Abdullah’s Children’s Hospice (BACCH), founded in 2012 by philanthropists Dame Margaret and Dr. Hilal AlSayer, is one of

a handful of hubs for pediatric palliative care in the Gulf region. BACCH offers comprehensive, multidisciplinary care to all children in Kuwait, irrespective of their background or residency, and does so free of charge. Medical professionals in other government hospitals, such as Farwaniya Hospital's Pediatric Intensive Care Unit (PICU) and Neonatal Intensive Care Unit (NICU), as well as general pediatric departments at Sabah and Jahra Hospitals, are increasingly enthusiastic about integrating pediatric palliative care into their services. This growing interest signifies a promising shift towards a more holistic approach to healthcare for children in Kuwait.

PPC Services

In addition to medical care, PPC services also include emotional, social, and psychological support for the child and their family, particularly during end-of-life care. Music therapy, physical therapy, art experiences, child life, medical staff, psychologists, and volunteers are included. Although some families came from stricter religious backgrounds and may not have received music therapy well, families were pleasantly surprised by our services; music therapy was new to them and well-received.

Family-centered care is a cornerstone of PPC. It acknowledges that the family is a crucial component of the care team for the child and includes them in the decision-making process, giving them a sense of being heard and valued. This method recognizes that families need assistance and resources as they negotiate the difficulties of caring for a child with a life-limiting or terminal disease. In addition to medical care, PPC services also include emotional, social, and psychological support for the child and their family, particularly during end-of-life care.

Experiences of CCLS in PPC in Kuwait

Child Life Specialists (CLS) in PPC in Kuwait make invaluable contributions to the care landscape. Their role is multifaceted and indispensable, and their involvement has led to significant milestones. In 2021, I had the honor of introducing the first

psychosocial referral in our pediatric hospice's history, which had previously only accommodated medical referrals. This initiative aimed to address the essential emotional and psychological needs of young patients and their families during the early stages of the disease, as opposed to solely focusing on later stages. Moreover, during my tenure as Acting CLS there, our teams were able to transition services to Zoom to provide psychosocial support and individual and group play during the COVID-19 pandemic.

Through my extensive engagement with PPC families and caregivers, it becomes evident that they have an intense yearning for normalcy amidst the challenges of caring for a child with a life-limiting illness. These families seek moments of routine and everyday life, allowing them to create cherished memories and experiences, involving both the patient and their siblings. PPC services play a pivotal role in facilitating these opportunities by addressing the child's specific needs and abilities, as well as the broader family needs. This includes organizing outings, events, birthdays, and other activities that create positive



Author Maryam AlBahar, MS, CCLS supporting a child in the hospital playroom

memories and legacy-building opportunities for these families.

CLS professionals in Kuwait have also been proactive in awareness campaigns and organizing engaging events, such as teddy bear clinics, to foster comfort and understanding among children facing complex medical conditions. CLS professionals excel at planning activities that normalize family experiences and memory creation. They advocate for each child's unique needs, organize respite weekends, and collaborate closely with medical and physiotherapy teams. Moreover, they liaise with kitchen staff to ensure meals align with young patients' dietary requirements and preferences.

However, CLS professionals face challenges. Adapting their schedules to meet the evolving medical needs of young patients can be demanding. Occasional difficulties in collaborating with certain medical staff members are encountered. Additionally, recognition and career growth for psychosocial staff remain areas of improvement within the workplace. Nevertheless, despite these challenges, CLS professionals remain dedicated to instilling joy and positivity in the lives of PPC patients and their families, offering hope amidst the complex landscape of PPC in Kuwait.

Advancing Pediatric Palliative Care in Kuwait

The future of PPC services in Kuwait is brimming with promise. Both private and government hospitals can significantly benefit from adding PPC specialists to bolster the workforce. Expanding the numbers of CLS and enhancing psychosocial services, including incorporating specialists like Music Therapists and Art Therapists, represents a significant stride forward. A key component of this advancement involves fostering collaboration with regional and international colleagues and organizations, as this is paramount for knowledge exchange and global networking. Enlisting experts to provide training for medical teams and support local CLS internships and training initiatives will further fortify the field. Lastly, investing in research that is specifically focused on the unique needs of regional patients will pave the way for the delivery of truly customized care to our children and their families. Together, these strategic measures can position regional healthcare services on the forefront of progressive pediatric palliative care, ensuring a brighter and healthier future for our community.

